**Palliative Lung Cancer Care:**

**Patient, Family and Carer Information**

A diagnosis of lung cancer can be life-changing for you and for the people close to you. You are not alone, and it is important that you know what kind of support is available.

With this information resource, we hope that we can:

* Help you to understand what Palliative Cancer Care is.
* Help you to know what kind of care and support is available to you, and how to access it.
* Support you to consider what is most important to you going forward.

**What is Palliative Cancer Care?**

Palliative Cancer Care is care and support for people living with a cancer that cannot be cured. It also includes care for the people that they are close to. Often this is family, but not always.

Treatments such as chemotherapy can be helpful at slowing down the growth and spread of cancer for some people. Radiotherapy can be helpful for managing a specific pain or managing other symptoms. As these treatments do not cure the cancer you may hear them called palliative treatments.

However, sometimes these treatments may not help, are no longer effective, or there are no further treatments available. Sometimes cancer treatments may not be safe, for example, if the person with cancer has other medical problems or is unwell or frail.

Some people with cancer may choose not to have treatment, especially if their doctor feels it is unlikely to help to make their life longer or better. Sometimes patients will want to try cancer treatments to see if they will help, but there is a risk that cancer symptoms may get worse rather than better. After a time, many cancer treatments lose their effect.

When treatment is not possible, or no longer possible, sometimes the term ‘Best Supportive Care’ is used. This means that the focus of care is not on treating the cancer itself; but instead on supporting the person living with cancer, and those they are close to. Sometimes this is also called ‘Palliative Care’ or ‘Palliative Cancer Care.’ Palliative Cancer Care is available to anyone with a cancer that cannot be cured, whether they are receiving cancer treatment or not. It includes:

* Help you and the people you care about come to terms with the diagnosis and what it means.
* Help with symptoms such as pain, breathlessness, tiredness, sickness or problems with eating.
* Help you to think about what matters most to you.
* Support to talk about the future and to plan ahead.
* Support you to manage at home.

Palliative Cancer Care is provided by a combination of people, including (but not limited to):

* General Practice Teams and District Nurses,
* Cancer Clinical Nurse Specialists
* Occupational Therapists
* Dietitians
* Physiotherapists
* Spiritual Care
* Counsellors
* Specialist Palliative Care
* There are many voluntary organisations such as Macmillan Cancer Support, Marie Curie, Maggie’s Centre, Carers’ Centres, and others who may also be part of your Palliative Cancer Care.

Your Cancer Nurse Specialist can discuss with you how your own Palliative Cancer Care might be provided. For people living at home, their GP and District Nurse are usually the main point of contact.

**What kind of care and support is available?**

**Cancer Clinical Nurse Specialists (CNS)**

Most people with lung cancer should have a designated Cancer Clinical Nurse Specialist, sometimes called the ‘CNS’.

Often Cancer CNS support people through their pathway to diagnosis and also through cancer treatment. When cancer treatment is not possible, or no longer possible, you may still find it beneficial to have some contact with your Cancer CNS. Usually this is by phone or through clinic appointments at the hospital. The Cancer CNS are in close communication with your primary care team and other health professionals as needed.

However, most people with cancer who are not having treatment find that coming to hospital for appointments becomes less helpful. It may also become too difficult or exhausting. For this reason, most Palliative Cancer Care is provided by your General Practice Team and District Nurse Team in the community.

**General Practice Teams**

Your General Practice Team is an important part of your Palliative Cancer Care. General Practice teams are made up of a variety of professionals including GPs, Nurse Practitioners, Practice Nurses, Pharmacists, Paramedics and other Allied Health Professionals.

Not every General Practice team is the same. They may know you from before your cancer diagnosis, or have supported you through your diagnosis and/or treatment. Or, you may not have needed an ongoing relationship with your General Practice team before now.

Whatever your situation was previously, your General Practice team should be aware of your cancer diagnosis and be able to support you going forward. The team will help guide you to get the right care from the most appropriate person in the team. This might not always be the GP. We want you to get the right care, in the right place at the right time to suit your needs.

General Practice Teams can provide a range of palliative care and support including:

* Leading your palliative care at different stages of your illness, including visiting you at home.
* Assessing and managing your symptoms.
* Reviewing your medications and stopping any which are not likely to benefit you.
* Talking about future appointments you may have with hospital/wider teams and agreeing with you which ones are likely to be helpful and which ones may not be.
* Talking about what matters to you, and what your preferences might be around your future care (see ‘Future Care Planning’ section, below).
* Supporting your family.
* Recording your wishes for your future care in your health record, in an ‘electronic Key Information Summary’ (eKIS) section. This can be accessed by other healthcare teams looking after you, especially when your GP surgery is closed. It can help to make sure that your care going forward is the kind of care that you would choose. For many people, this involves most care being at home and less time in hospital.
* Talking about, and arranging, ‘just in case’ medications at home. These are medications that can be given by District Nurses by injection if you have difficult symptoms or trouble swallowing your normal medications.
* Talking to you about resuscitation and recording a decision in your medical records. Cardiopulmonary resuscitation is a treatment that benefits some people but can cause harm to others. When people are nearing the end of their lives with a cancer that cannot be cured, resuscitation is usually not helpful. Follow link to the Scottish Government Information Leaflet for Patients, their Relatives and Carers- [Decisions about cardiopulmonary resuscitation.](https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2016/08/decisions-cardiopulmonary-resuscitation-information-patients-relatives-carers/documents/00504968-pdf/00504968-pdf/govscot%3Adocument/00504968.pdf)

**District Nursing**

Your District Nursing team is an important part of your Palliative Cancer Care, providing care and support in the community 24 hours a day, 7 days a week. This is through a combination of phone calls and home visits. District Nurses provide a range of palliative care including:

* Practical support to help you to manage in your home, assessing your need for personal care, assessing your need for basic equipment such as shower chairs, toilet frames and hospital beds.
* Emotional support for you and your relatives or other close people, adjusting to your diagnosis and changing health.
* Clinical support e.g. assessing and managing symptoms (including administering medications by injection if this is needed), managing any wounds or catheter issues.
* Care coordination by working with your GP and other teams as needed, such as Specialist Palliative Care, Occupational Therapy and others (see below).

Your GP or Cancer CNS can refer you to your District Nurse, or you can self-refer by phoning your GP surgery and asking to be put through to the District Nurse team.

**Specialist Palliative Care**

Specialist Palliative Care services are made up of multi-disciplinary teams of clinicians who support patients and families with more complex needs, in all care and residential settings, including:

* Acute hospitals
* Community hospitals
* Care homes
* People’s own homes
* Hospices

Care and support is provided by specialist nurses, healthcare assistants, doctors, occupational therapists, physiotherapists, dietitians, specialist pharmacists, counsellors, spiritual care, complementary therapists and volunteers.

Specialist Palliative Care is available to those who need an extra level of clinical care and/or support, beyond the care provided by their GP, District Nurses, Cancer CNS or other teams. Many people with incurable cancer do not need Specialist Palliative Care as their other care providers are able to meet their palliative care needs. Any GP, District Nurse or other healthcare professional who feels that their patient requires specialist support can get in touch with their local Specialist Palliative Care team.

Hospices offer inpatient care for people who require intensive specialist input. This can be for symptom management where symptoms are particularly difficult, but it can also be when the person and their family or carers are experiencing other difficulties such as significant anxiety or distress. Many people who use the hospice come in for one to two weeks to have their symptoms managed, before returning home or to another place of care. Others are admitted at the end of their lives and die in the hospice. Most people do not require hospice care, but it is available to people whose palliative care needs cannot be met in another setting.

Inpatient palliative care is provided in many other settings, such as acute and community hospitals. Specialist Palliative Care teams provide advice for staff in any of these settings, 7 days a week.

**Occupational Therapy**

**Details for your region:**

When the ability to carry out our normal activities of daily living (occupation) is affected by illness (including lung cancer), it can also affect physical, psychological and emotional well-being. Occupational therapy interventions are symptom-led and a problem solving approach is used to help with everyday activities that people may be finding difficult (such as difficulty washing and dressing, cooking, getting around their home, as well as activities for enjoyment). We use a holistic, person centred approach is to set goals, optimise functional ability, improve quality of life and provide a sense of control. This may involve adapting the way we manage tasks and/or using equipment to make activities less effortful.

If there is already an Occupational therapist (OT) involved in a person’s care, they may be able to meet their palliative care needs. Support from a community OT can be accessed through local council teams. Some people require Specialist Palliative Care OT input. Each person’s usual care team (GP Team, District Nurse, hospital or wider community teams) can contact their local service if this is needed.

**Support around Nutrition**

Eating can be difficult for people with incurable lung cancer. Weight loss is common and it can be worrying for you and your family. Struggling with eating can affect many aspects of life, such as socialising and spending time with family and friends.

Your healthcare team, including your Cancer CNS, GP Team and District Nurse, can offer general advice about your appetite and weight loss. They can also provide written advice specific to your diagnosis and stage of illness.

When people are having lung cancer treatment, maintaining a good level of nutrition and slowing weight loss can help to reduce treatment side effects and can also help them to stay well. When lung cancer is more advanced, and there is no cancer treatment, or no more treatment, a different approach may be needed. For most people who are deteriorating because of their lung cancer, eating more will not increase energy levels or improve quality of life. Oral nutritional supplements (such as ‘build up’ drinks) are usually not helpful for people with advanced lung cancer, apart from in specific situations (e.g difficulty swallowing solid food).

Your healthcare team can refer you to a dietitian if you have any ongoing concerns about your nutrition or if any of your symptoms affect your eating or enjoyment of food. Dietitians can also help you and your family to cope with eating or nutritional problems. They can explain how eating can be affected by lung cancer and can give practical advice to make mealtimes more positive.

**Physiotherapy**

Physiotherapy focuses on maintaining and improving movement, function and strength. Physiotherapists will look at maintaining and improving mobility as well as providing self management strategies for symptoms.

Physiotherapists will also aid in supporting patients to remain at home for as long as possible as well as support if mobility starts to worsen. We can provide some equipment to aid with maintaining independence for functional activities such as mobility and washing/dressing.

Any GP Team member, District Nurse, Cancer CNS or wider clinician can refer a patient for a physiotherapy assessment. This may be offered through the hospital physiotherapy teams or, in the community, through Social Care or Specialist Palliative Care.

**Social Care**

Social Care Social care services are there to help support you at home, to work out what your needs are and to help to identify what is available to you within your local area. This may include support to help you with jobs such as cleaning and cooking. It may also be to help support you with some personal tasks such as washing and dressing. Your GP or District Nurse can refer you, or you can self refer by contacting your local social work department.

**Details for your region:**

**Counsellor**

Counselling allows people to explore conscious and unconscious thoughts to help them to process issues causing concern or distress. Counselling helps people to gain insight into their feelings, to normalise their reactions and to develop strategies for coping with the changes an illness brings to people and their families.

Counselling for people affected by lung cancer is available through a range of services, including Specialist Palliative Care.

Your GP, District Nurse and Cancer CNS can help to advise you on which service may be most helpful for you. They can also refer you to the most appropriate service. This can be for the person with cancer, but also for their relatives and carers, including in bereavement.

**Details for your region:**

**Children and Families’ Support**

Children and Families’ Support Services are usually provided through Specialist Palliative Care. They offer support, information and advice for people with lung cancer, their partners and co-parents, children, stepchildren and young people facing the death of a parent or adult caregiver. They also provide support in bereavement.

Parents may face helping their children understand the nature of the illness, adjust to changes in the ability of their ill parent and having to prepare them to say goodbye. Common concerns explored include making sense of what is happening, making sense of personal and family history; adjusting to changes in physical ability, exploring emotional reactions, making relationship adjustments and identifying wishes and hopes for the future. Work might involve, for example, helping the patient to put together written or recorded material to leave for the family. Information and support can also be offered to young people and occasionally directly to children themselves.

Support can start or continue at any point during the bereavement process through individual and family counselling and bereavement groups.

**Details for your region:**

**Spiritual Care**

Spiritual Care helps people to find, or re-find, meaning, purpose and hope at any stage of life or illness. Spiritual Care is for everyone, not just religious people.  Faith and belief are just one of many different ways that people make sense of the world.  Chaplains can help facilitate religious care if that is helpful, but are available to everyone, including those with no religious faith.

All healthcare professionals provide spiritual care as part of the whole-person care they give.  Chaplains can be a resource to help fellow healthcare professionals provide that care for others, or are available as a specialist to support someone directly.

When our spiritual needs are met, it’s often described as being at peace.  At peace about how things are doesn’t mean we necessarily like what’s happening or wouldn’t want things to be different.  Rather, that we’ve come to terms with things and are living well in the moment.

Any healthcare professional can refer you or your close person for Spiritual Care support.

**Details for your region:**

**Charities**

* [Maggie’s Centre](https://www.maggies.org/)
* [Macmillan](https://www.macmillan.org.uk/cancer-information-and-support/supporting-someone)
* [Marie Curie](https://www.mariecurie.org.uk/help/support)
* [Roy Castle: Lung Cancer Foundation](https://roycastle.org/help-and-support/)

**Future Care Planning (previously known as Anticipatory Care Planning, or ACP)**

When you, your family member or someone you are caring for is affected by lung cancer that cannot be cured, it can be helpful to start to think ahead.

**What is important to you?**

Many people wish to plan ahead, even although the future may be uncertain. It is often helpful to think about what is important to you and talk about this with the people close to you.

Thinking about your answers to the following questions can help when you talk with healthcare professionals about your care:

* What do you know about your lung cancer?
* What really matters to you when you think about your health?
* What matters to you the most when thinking about your future?

If you feel that you do not know enough about your illness, or how things are likely to change with time, a conversation with your Cancer CNS or GP or another professional should help. It is almost impossible to predict exactly how you will change with time, but there are some features of advancing cancer that are very common, and most people find it helpful to talk these through. Usually, the more people understand, the more able they are to think and plan ahead.

Some people find it reassuring to make plans and know they have sorted things out for the future, for example putting your affairs in order, considering life insurance/pension policies and thinking about a will and funeral plans.

You may also want to consider appointing a Power of Attorney (POA), allowing a chosen person to make decisions for you, if you are no longer able. This can be emotional, but talking about your wishes can make it easier for your family or loved ones to know how and where you would like to be cared for at the end of your life. We know that people who are able to plan ahead are more likely to have the kind of care they would choose when they become less well. For many people, this involves spending less time in hospital and more time at home.

Home is where most people with advanced illness spend most of their time. It is also where most people would choose to be. However, as time goes on, people’s needs change and in order to stay at home and to be comfortable, it may become necessary to accept some help. This may be in the form of equipment, or perhaps carers coming in to your home. It may also involve nurses, doctors and others visiting you at home to help with managing your symptoms or for wider support.

Sometimes being at home becomes too difficult and an admission to a care home, hospital or hospice is needed. Sometimes this becomes a permanent move, but often it may be for a period of assessment, whilst your needs are assessed. It is helpful to think whether you would be open to this, if your situation changes, and to talk about what your options might be with your team. As there is always some uncertainty about how you and your needs will change, it can be helpful to keep an open mind about what your care might need to look like in the future.

As well as your health needs, it can be helpful to think about the things that bring you pleasure in life, whatever they may be. For most people, maintaining some quality of life as their cancer advances is possible, even though life might look and feel very different to how it did before.

Please remember that you are not alone and that you and your family and carers are entitled to feel informed, cared for and supported.